

Report of Year One of the International Institute for Indigenous Resource Management ELSI Program

DOE Genome Contractor-Grantee Workshop IX

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What we're trying to accomplish

- Dialogues
- Research
- Capacity building
- Information dissemination

Dialogues

- Conduct a series of facilitated dialogues with tribal leadership and staff to examine the cultural, religious, economic, social, legal and other issues related to the Human Genome Project and to set out a tribal research agenda on these issues.

Research

- Conduct research to identify the cultural, social, historical, economic, political and other factors which affect Indian and tribal perceptions of the human genome project and genetic research.

Capacity building

- Build tribal capacity to identify genetic issues embedded in public health and safety, scientific, and environmental decision-making by conducting a series of workshops and preparing briefing materials to familiarize different tribal audiences with the human genome project and genetic research.

Information dissemination

- Disseminate the results of such research and analyses through the print and electronic media, through written reports and through presentations at tribal, professional and other meetings, conferences, symposia and seminars.

Dialogues with native peoples

- University of Colorado Health Sciences Center and IIRM Conference, Aspen, Colorado
- University of British Columbia, Vancouver, British Columbia
- IIRM Roundtable on Intellectual Property, Denver, Colorado
- IIRM Roundtable on Sacred Landscapes, Denver, Colorado

Capacity Building: developing the indigenous human resource

- University Fellows: provides opportunity for native teachers to do research on indigenous ELSI issues and serve as mentors to junior staff and interns.
- Internships: gives students and recent graduates opportunity to team with senior scholars on cutting edge research projects.

Research and publications

- Genetics, Culture and Identity in Indian Country
- An Introduction to Alternative Mechanisms for Protecting the Intellectual Property of American Indians in The Context of the Human Genome Project
- Traditional Indian Law, The Intellectual Property Regime, and the Protection of Indigenous Genetic Materials
- Tattooed Heads, Scalps, Kidneys and Genetic Material: A Brief History of Commerce in Body Parts and the Implications for Regulating the Genome of Indigenous Peoples in Indian Country

Dissemination

- Website: www.iiirm.org
- International Congress of Ethnobotanists Conference, Athens, Georgia
- A Decade of ELSI Research, NHGRI, Bethesda, Maryland
- The Cancer Family: At the Intersection of Science & Society, University of Virginia, Charlottesville, Virginia

Research projects suggested by IIIRM dialogues

- Organization and Operation Of Tribal Tissue Banks: Legal and Regulatory Requirements
- An Annotated Tribal Informed Consent Model
- Tribal Control and Management of Genetic Materials Under Customary Law
- Financing and Control of Pharmaco-genetic Research
- An Assessment of What and How Many Patents Have Been Issued Based On Indian Genetic Materials
- An Assessment of Scientific Research Projects Based on Indian Genetic Materials

What we're planning to do

- Roundtable on native genetic research priorities (with the University of Colorado Health Sciences Center, University of British Columbia, and Health Canada)
- Roundtable on responsible investing (with NYU Law School's Institute for Law & Society)

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